Center for Children with Special Needs A Program of



Dear Parents,

This Care Notebook has been developed just for you—parents with children with special health care needs. We offer this Notebook to you with deep appreciation for the central role you play in the life and care of your child. We hope it will serve as a guide in organizing and keeping track of your child's records, appointments, and other important information. The Care Notebook is produced by the Center for Children with Special Needs and the Washington State Department of Health, Children with Special Health Care Needs Program, with invaluable input from parents and community professionals.

Families tell us they value having a central place to keep information they can easily take to appointments.

"I used a paper bag for my file! It took forever to find what I needed! Now I can just turn to the right section."

"This way I don't have to keep it all in my head."

"I'd use the notebook to organize my thoughts and concerns before a doctor's appointment. It gave me confidence and credibility."

Families also use the Notebook to improve communication with doctors and other health care providers.

"Didn't have to repeat information...I've taken it to all the doctors and when they ask what happened, I just pull out the notebook and show them."

"I use the notes as a diary. I write down what the doctor has said, word for word. This really helps when I go to the next doctor and he wants to know what that doctor said."

We encourage you to make this Notebook work for you! Create your own sections; remove and rearrange pages to fit your needs; and personalize it with drawings, stickers, photographs, and special articles and resources you've found helpful. The Care Notebook pages may be downloaded and printed from http://www.cshcn.org. You can find other resources and information for you and your family at this website.

If you have suggestions or comments about the Care Notebook, please feel free to contact Megan Sety at (206) 987-5310 or megan.sety@seattlechildrens.org.

Most sincerely,

Kathy Fennell Manager Megan Sety Program Assistant

Care Notebook: A Quick Guide

What is a Care Notebook?

A Care Notebook is an organizing tool for families who have children with special health care needs. Use a Care Notebook to keep track of important information about your child's health and care.

How can a Care Notebook help me?

In caring for your child with special health needs, you may get information and paperwork from many sources. A Care Notebook helps you organize the most important information in a central place. A Care Notebook makes it easier for you to find and share key information with others who are part of your child's care team.

Use your Care Notebook to:

- ☐ Track changes in your child's medicines or treatments
- ☐ List telephone numbers for health care providers and community organizations
- Prepare for appointments
- ☐ File information about your child's health history
- ☐ Share new information with your child's primary doctor, public health or school nurse, daycare staff, and others caring for your child

What are some helpful hints for using my child's Care Notebook?

- ☐ Store the Care Notebook where it is easy to find.

 This helps you and anyone who needs information in your absence.
- □ Add new information to the Care Notebook whenever there is a change in your child's treatment.
- ☐ Consider taking the Care Notebook with you to appointments and hospital visits so that information you need will be close at hand.

How do I set up my child's Care Notebook?

Follow these steps to set up your child's notebook:

Step 1: Gather information you already have.

☐ Gather up any health information you already have about your child. This may include reports from recent doctor's visits, immunization records, recent summary of a hospital stay, this year's school plan, test results, or informational pamphlets.

Step 2: Look through the pages of the Care Notebook.

- Which of these pages could help you keep track of information about your child's health or care?
- □ Choose the pages you like. Print copies of any that you think you will use. The Care Notebook pages are available from the Internet at http://www.cshcn.org. Go to "Resources" and then choose "Care Organizing Tools."

Step 3: Decide which information about your child is most important to keep in the Care Notebook.

- ☐ What information do you look up often?
- What information is needed by others caring for your child?
- ☐ Consider storing other information in a file drawer or box where you can find it if needed.

Step 4: Put the Care Notebook together.

- □ Everyone has a different way of organizing information. The only important thing is to make it easy for <u>you</u> to find again. Here are some suggestions for supplies used to create a Care Notebook:
- □ 3-ring notebook or large accordion envelope. Hold papers securely.
- <u>tabbed dividers</u>. Create your own information sections.
- □ pocket dividers. Store reports.
- □ <u>plastic pages</u>. Store business cards and photographs.

Care Notebook List of Pages

Pages to Keep Track of Appointments and Care	Pages to Create a Care Team and Resources List	
□ Appointment Log	☐ Children's Hospital and Regional Medical	
□ Diet Tracking Form	Center	
□ Emergency Information Form	Community Health Care/Service Providers:	
□ Equipment/Supplies	☐ Medical/Dental	
☐ Growth Tracking Form	□ Public Health	
☐ Hospital Stay Tracking Form	☐ Home Care	
☐ Lab Work/Tests/Procedures	☐ Therapists	
☐ Make-a-Calendar	Early Intervention Services	
☐ Medical Bill Tracking Form	□ School	
☐ Medical/Surgical Highlights	☐ Child Care	
☐ Medications	□ Respite Care	
□ Notes	□ Pharmacy	
Pages to Create a Care Summary: Abilities and Special Care Needs	□ Special Transportation□ Family Information	
☐ Activities of Daily Living	□ Family Support Resources	
☐ Care Schedule	□ Funding Sources	
□ Child's Page—Now and Later	☐ Alphabet Soup Acronym Index	
□ Communication		
□ Coping/Stress Tolerance		
□ Mobility		
□ Nutrition		
□ Respiratory		
□ Rest/Sleep		
□ Social/Play		
☐ Transitions—Looking Ahead		

Family Information

Child's Name:	Nickname:	
	Social Security Number:	
Legal Guardian:		
	Phone:	
Family Members		
Mother's Name:		
Social Security Number:		
Address:		
	Evening Phone:	
Father's Name:		
Social Security Number:		
Address:		
Daytime Phone:	Evening Phone:	
• Sibling's Name:	Age: Name:	Age:
• Sibling's Name:	Age: Name:	Age:
Other household members:		
Important Family Information:		
Interpreter Needed? Yes:		
Interpreter:	Phone:	
Emergency Contact		
• Name:		
	Evening Phone:	

Family Support Resources

Parent to Parent:		
Contact Person:		
Address:		
Phone:	Fax:	
Parent Group:		
	Fax:	
Religious Organization:		
Contact Person:		
Address:		
	Fax:	
Service Organization:		
Address:		
Phone:	Fax:	
Counseling Services:		
Contact Person:		
Address:		
Phone:	Fax:	

(continued)

Family Support Resources

•	Division of Developmental Disabilities:	
	Contact Person:	
	Address:	
	Phone:Fa	X:
•	• Other:	
	Contact Person:	
	Address:	
	Phone· Fa	х.

Funding Sources

In a company of Name of	
Insurance Name:	
Address:	
Phone:	Fax:
Insurance Name:	
Policy Number:	
Contact Person / Title:	
Phone:	Fax:
Insurance Name:	
Phone:	Fax:
Supplemental Security Income (SSI):	
Contact Person / Title:	·
Address:	
Phone:	Fax:

(continued)

Funding Sources

• Other:		
Contact Person / Title:		
Address:		
Phone:	Fax:	
• Other:		
Contact Person / Title:		
Address:		
Phone:	Fax:	

Children's Hospital and Regional Medical Center

4800 Sand Point Way NE Seattle, WA 98105

Hospital Operator (206) 987-2000 or 1-866-987-2000 Resource Line (206) 987-2500 or 1-866-987-2500 Emergency Room (206) 987-2222

Medical Record	Number:		
• CHRMC C	Clinic:		
Date of Fi	rst Visit:		
Physician:			
Contact P	erson / Title:		
		Fax:	
• CHRMC C	Clinic:		
Date of Fi	rst Visit:		
Physician:			
Phone:		Fax:	
• CHRMC C	Clinic:		
Date of Fi	rst Visit:		
Physician:			
Contact P	erson / Title:		
Phone:		Fav	

Medical / Dental **Community Health Care Providers**

Primary / Community Care Provide	r:	
Date of First Visit:		
Phone:	Fax:	
Community Hospital:		
	Fax:	
Community Specialty Care Provide	er:	
Phone:	Fax:	
Community Specialty Care Provide	er:	
Address:		
Phone:	Fax:	
Dentist / Orthodontist:		
Phone:	Fax:	

Public Health Community Health Care / Service Providers

Public Health Department:		
		_
		_
Phone:	Fax:	_
Public Health Nurse:		
	Date of First Visit:	
Nutritionist:		_
Phone:	Date of First Visit:	
Social Worker:		
Phone:	Date of First Visit:	
• Other:		_
Phone:	Date of First Visit:	

Home Care Community Health Care / Service Providers

Home Nursing Agency:		
Start Date:		
Contact Person:		
Address:		
Phone:	Fax:	
Home Nursing Agency:		
Start Date:		
Contact Person:		
Address:		
Phone:	Fax:	
Home Nursing Agency:		
Start Date:		
Contact Person:		
Address:		
Phone:	Fax:	

Therapists

Community Health Care / Service Providers

pists:		
Occupational Therapist (OT):		
Start Date:		
Agency:		
	Fax:	
Physical Therapist (PT):		
Start Date:		
Agency:		
Address:		
	Fax:	
Speech-Language Pathologist:		
Start Date:		
Agency:		
Address:		
Phone:	Fax:	

Early Intervention Services Community Health Care / Service Providers

Developmental Center:	
Start Date:	
Contact Person:	
Address:	
Phone:	Fax:
Family Resources Coordinator:	
Start Date:	
Agency:	
Address:	
Phone:	Fax:

School

Community Health Care / Service Providers

School / Preschool:		
Start Date:		
Address:		
Phone:	Fax:	
• School Nurse:		
Phone:	Fax:	
Contact Person / Title:		
Phone:	Fax:	
Contact Person / Title:		
Phone:	Fax:	

Child Care Community Health Care / Service Providers

Child Care Provider:		
Start Date:		
Contact Person:		
Address:		
Phone:	Fax:	
Child Care Provider:		
Start Date:		
Contact Person:		
Address:		
Phone:	Fax:	
Child Care Provider:		
Start Date:		
Contact Person:		
Address:		
Phone.	Fax [.]	

Respite Care Community Health Care / Service Providers

Respite Care Provider:		
Start Date:		
Contact Person:		
Agency:		
Address:		
Phone:	Fax:	
Respite Care Provider:		
Start Date:		
Contact Person:		
Agency:		
Address:		
Phone:	Fax:	
Respite Care Provider:		
Start Date:		
Contact Person:		
Agency:		
Address:		
Phone:	Fax:	

Pharmacy Community Health Care / Service Providers

• Pharmacy:		
Phone:	Fax:	
Pharmacy:		
Contact Person:		
Address:		
Phone:	Fax:	
Pharmacy:		
Contact Person:		
Address:		
-		
Phone:	Fax [.]	

Special Transportation Community Health Care / Service Providers

Transportation (to and from medical / therapy appointments)
Contact Person:
Agency:
Address:
Phone:Fax:
Transportation (to and from medical / therapy appointments)
Contact Person:
Agency:
Address:
Phone: Fay:

Alphabet Soup Acronym Index

The following index lists a wide variety of acronyms used by professionals who work with families.

ACCH Association for the Care of Children's Health

ADA Americans with Disabilities Act
ADD Attention Deficit Disorder

ADHD Attention Deficit Hyperactivity Disorder
AFDC Aid to Families with Dependent Children
AIDS Acquired Immune Deficiency Syndrome

ARC The Arc: Advocates for the Rights of Citizens with Developmental Disabilities and their families

ARNP Advanced Registered Nurse Practitioner

BIA Bureau of Indian Affairs
BD Behaviorally Disabled

CAP Community Alternative Program (Medicaid), Community Action Program (Dept. of Community

Development), Client Assistance Program (Division of Vocational Rehabilitation)

CD Communication Disorders

CDS Communication Disorders Specialist
CEC Council for Exceptional Children
CFR Code of Federal Regulations

CHAP Children Have a Potential (Air Force assistance program)

CHDD Center on Human Development and Disability at the University of Washington

CHRMC Children's Hospital and Regional Medical Center

CP Cerebral Palsy

CPS Child Protective Services

CSHCN Children with Special Health Care Needs
CSO Community Service Office, DSHS
DCD Department of Community Development

DCD Department of Community Development DCFS Division of Children and Family Services

DD Developmentally Disabled

DDD Division of Developmental Disabilities, DSHS
DDPC Developmental Disabilities Planning Council

DH Developmentally Handicapped
DMH Division of Mental Health
DOH Department of Health

DSB Department of Services for the Blind
DSHS Department of Social and Health Services
DVR Division of Vocational Rehabilitation

ECDAW Early Childhood Development Association of Washington ECEAP Early Childhood Education and Assistance Program

ED Emotionally Disturbed EEG Electroencephalogram

EEU Experimental Education Unit, CHDD

EFMP Exceptional Family Member Program (helps military families locate to areas with services)

EKG Electrocardiogram

EPSDT Early Periodic Screening, Diagnosis, and Treatment

ESD Educational Service District
FAPE Free Appropriate Public Education
FRC Family Resources Coordinator
HHS Health and Human Services
HI Health Impaired or Hearing Impaired
HMO Health Maintenance Organization

HO Healthy Options, DSHS, Medicaid Managed Care Program

HOH Hard of Hearing

ICC Interagency Coordinating Council; county ICC and state ICC.

IDEA Individuals with Disabilities Education Act

IEP Individual Education Plan
IFSP Individual Family Service Plan

(continued)

Alphabet Soup Acronym Index

I & R Information and Referral ISP Individual Service Plan LD Learning Disabled

LDA Learning Disabilities Association

LEA Local Education Agency

LICWAC Local Indian Child Welfare Advocacy Board

LRE Least Restrictive Environment MAA Medical Assistance Administration

MCH Maternal and Child Health

MD Medical Doctor

MDT Multi-Disciplinary Team
MH Multiply Handicapped
MR Mentally Retarded
MS Multiple Sclerosis

NICU Neonatal Intensive Care Unit

OCR Office of Civil Rights

OFM Office of Financial Management

OI Orthopedically Impaired

OSEP Office of Special Education Programs

OSERS Office of Special Education and Rehabilitation Services

OSPI Office of Superintendent of Public Instruction

OT Occupational Therapy/Therapist

OTR Licensed and Registered Occupational Therapist

PAVE Parents Are Vital in Education
P & A Protection and Advocacy

PFTH Program for the Handicapped (military program)

PHN Public Health Nurse

PL Public Law

PT Physical Therapy/Therapist
PTA Parent Teacher Association

RCW Revised Code of Washington (state law)

RN Registered Nurse

RPT Registered Physical Therapist SBD Seriously Behaviorally Disabled

SEA State Education Agency

SEAC Special Education Advisory Council

SEPAC Special Education Parent/Professional Advisory Council

SLD Specific Learning Disability
SSA Social Security Administration

SSI Social Security Income

STOMP Specialized Training of Military Parents

SW Social Work/Worker

TAPP Technical Assistance for Parents and Professionals
TASH The Association for Persons with Severe Handicaps

TBI Traumatic Brain Injury

TDD Telecommunication Device for the Deaf

TTY Telecommunication Device for Deaf, Hearing Impaired, and Speech Impaired Persons

VI Visually Impaired

WAC Washington Administrative Code

WACD Washington Association for Citizens with Disabilities
WIC Women, Infants and Children Supplemental Food Program

WSMC Washington State Migrant Council
WSSB Washington State School for the Blind

This list was adapted from and used with permission of PAVE.

Medical / Surgical Highlights

DATE	PROCEDURE	RESULT	COMMENTS

Lab Work / Tests / Procedures

DATE	TEST	RESULT	COMMENTS

Equipment / Supplies

Name of Equipment:		
Description (brand name, size, etc.):_		
Date obtained:	Supplier:	
		Phone:
Name of Equipment:		
Description (brand name, size, etc.):_		
Contact Person:		Phone:
Name of Equipment:		
Description (brand name, size, etc.):_		
Contact Person:		Phone:
Name of Equipment:		
Contact Person:		Phone:

Appointment Log

DATE	PROVIDER	REASON SEEN / CARE PROVIDED	NEXT APPOINTMENT

Care Schedule

TIME	CADE
TIME	CARE
Morning	
Afternoon	

Care Schedule

TIME	CARE
Evening	0,1112
Lverning	
Night	

Growth Tracking Form

DATE	HEIGHT	WEIGHT	HEAD CIRCUMFERENCE	CHECKED BY

Care Summary: Activities of Daily Living

bathroom, comb hair, brush teeth, etc. Describe what your child can do by him or herself and any help o equipment your child uses for these activities. Describe any special routines your child has for bathtime getting dressed, etc.
Date:

Use this page to talk about your child's abilities to feed him or herself, bathe, get dressed, use the

Care Summary: Nutrition

Use this page to talk about your child's nutritional needs. Describe foods and any nutritional formulas you child takes, any food allergies or restrictions, and any special feeding techniques, precautions, or equipment used for feedings. Describe any special mealtime routines your family and child have.
Date:

Care Summary: Respiratory

Use this page to talk about your child's respiratory care needs. Describe the care or treatments your child needs and any special techniques or precautions you use when giving care. Include any special routines your child has for respiratory care.
Date:

Care Summary: Communication

Use this page to talk about your child's ability to communicate and to understand others. Describe how you child communicates. Include sign language words, gestures, or any equipment or help your child uses communicate or understand others. Include any special words your family and child use to describe things
Date:

Care Summary: Mobility

Use this page to talk about your child's ability to get around. Describe how your child gets around. Includ what your child can do by him or herself and any help or equipment your child uses to get around. Describ any activity limits and any special routines your child has for transfers, pressure releases, positioning, etc.				
Date:				

Care Summary: Rest / Sleep

Use this page to talk about your child's ability to get to sleep and to sleep through the night. Describe you child's bedtime routine and any security or comfort objects your child uses.				
Date:				
· 				
-				

Care Summary: Social / Play

Ise this page to talk about your child's ability to get along with others. Describe how your child shows ffection, shares feelings, or plays with other children. Describe what works best to help your child ge long or cooperate with others. Describe your child's favorite things to do. Include any special family ctivities or customs that are important.
Date:

Care Summary: Coping / Stress Tolerance

Use this page to talk about how your child copes with stress. Stressful events might include new people or situations, a hospital stay, or procedures such as having blood drawn. Describe what things upset your child and what your child does when upset or when he or she has "had enough". Describe your child's way of asking for help and things to do or say to comfort your child.				
Date:				

Care Summary: Transitions—Looking Ahead

Your child and family will experience many transitions, small and large, over the years. Three predictable transitions occur: when your child reaches school age, when he or she approaches adolescence, and when your child moves from adolescence into adulthood. Other transitions may involve moving into new programs, working with new agencies and care providers, or making new friends. Transitions involve changes: adding new expectations, responsibilities, or resources, and letting go of others.

It's not always easy to think about the future. There may be many things, including what has to be done today, that keep you from looking ahead. It may be helpful to take some time to jot down a few ideas about your child's and family's future. You might start by thinking about your child's and family's strengths. How can these strengths help you plan for "what's next" and for reaching long term goals? What are your dreams and your fears about your child's and family's future?

Date:	-

Developed in partnership with staff from the Adolescent Health and Transition Project

Care Summary: Child's Page—Now and Later

Use this page for your child's words and thoughts about his or her life now as well as later. What are your child's dreams? What does he or she do well now that might give direction for life later? What does your child want to be when he or she grows up? Date:

Developed in partnership with staff from the Adolescent Health and Transition Project

Notes		

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Medical Bill Tracking Form

DATE	PROVIDER	COST	INSURANCE PAID	DATE PAID	FAMILY OWES	DATE PAID

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Hospital Stay Tracking Form

DATE	HOSPITAL	REASON	NOTES

Medications

Allergies:						
Pharmacy: Phone:						
DATE STARTED	DATE STOPPED	MEDICATION	DOSE / ROUTE	TIME GIVEN	PRESCRIBED BY	

.....

Diet Tracking Form

DATE	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
Tube Feeding							
Breakfast							
Lunch							
Dinner							
Snacks							
Notes							

"MAKE-A-CALENDAR"

..................

MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY